Long Term Care Now and the Next Generation



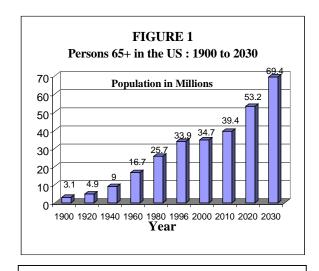
EXECUTIVE SUMMARY

Q) Who Needs Long Term Care Information and Education?

A) Baby Boomers

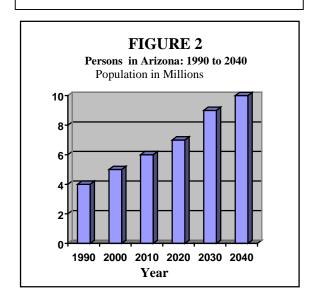
lder adults, those ages 65 and older, are the fastest growing segment of the U.S. population. This dramatic increase is fueled by the famous Baby Boomer Generation (those born between 1946 and 1964) who will begin to turn 65 in 2011. The U.S. Bureau of Census estimates that by 2030 nearly 20% of the population will be older than 65. Obviously, these changes will produce an enormous increase in demand for LTC services. Is the country prepared for this? Is Arizona?

ike the United States., Arizona is not only growing, but is growing older as well. Arizona's population is expected to reach 9 million by 2040 at which time about 20%, or nearly 2 million, will be older than 65. This 169% growth in the older population means a burgeoning reliance on LTC programs. The Arizona Long Term Care System (ALTCS, a part of Arizona's Medicaid), currently serving approximately 19,000 individuals who are elderly and physically disabled. The LTC system now covers about 4% of the individuals served by Arizona's Medicaid. but consumes approximately 30% of the entire Medicaid budget. The significant cost of LTC services and the expectation of still greater costs as the population grows, subjects this program to a high level of public, private, and legislative scrutiny.



Based on current trends, by the year 2020 up to 14 million elderly will need long term care – double the seven million who need long term care today.

<u>Chronic Care in America</u>, Robert Wood Johnson Foundation, 1996.



Are Arizona's Baby Boomers Planning for LTC Needs?

groups. There is a growing body of research indicating that Baby Boomers are consumed by day-to-day activities and expenses and as such, have given little thought to planning for the possibility of long term care. According to a 1997 study conducted in Minnesota, Baby Boomers have convinced themselves that they probably will never go to a nursing home or need other long term care services.

Participants in the Baby Boomer focus groups expressed belief in this same sense of invincibility. They had little knowledge of how the LTC system worked in Arizona, and they did not know who provided it or paid for these services. However, they quickly realized that they would be wise to reconsider the need to have this information and knowledge.

Among people who have chronic conditions, at least one in three does not understand what service they are eligible for, how to use them, or who provides them. A combination of financial issues, eligibility requirements and specific factors of individual conditions cause a significant number of chronically ill people to feel frustrated with the system designed to help them.

<u>Chronic Care in America</u>, Robert Wood Johnson Foundation, 1996.

Because of Arizona's rapidly aging population, there is a great need to plan for the future of Arizona's LTC system. In this study, AHCCCS set out to understand what kind of LTC information and services the Baby Boomer generation requires.

Invincibility?

"...It is much easier for me to think about (LTC) for people the age of my parents"

"Yeah, this does not happen to us"

"Just thought it would never be for

me"

Baby Boomer Focus Group Members



Is LTC Information both Available and Clear?

ot according to the focus group participants, who were very vocal about their frustration in trying to find information for either their family or friends. Both groups resoundingly told us that LTC information is:

- > Difficult to find,
- ➤ Not available or not helpful,
- Usually sought when there was a crisis such as having a family member in the hospital and needing more care at the time of discharge than the family could provide, and
- Difficult to navigate because it is not clear.

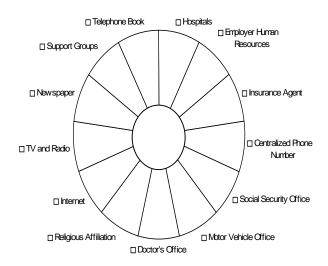
here to find information?

Focus group participants believed that a central "clearinghouse" would improve the accessibility of information. Such a system could direct individuals to the right agency at the most appropriate time.

Many of the focus group participants believed the primary sources of help and information were hospital social workers, employers, the Social Security Administration, and nonprofit organizations.

In addition, the participants stressed that written information should be available at the various sites (e.g., brochures on whom to contact for more information or lengthier documents on who can become eligible).

he following chart depicts the sources the focus group participants recommended for LTC information.



mong the many places a consumer can access LTC information is the Internet. Both focus groups repeatedly identified the Internet as a viable method for communicating with consumers, especially those with disabilities. This is further supported by a recent Harris Poll as shown in the dialog box below.

52 percent of disabled adults report the Internet has better informed them about the world versus 39 percent of adults without disabilities.

Health Care Purchaser, July 2000

What Should be the Role of the Government?

here were many opinions on the role of the private sector (business and industry), the public sector (government and community organizations), and individuals in paying for health care services. This was especially true for LTC services.

ccording to the participants, the government's role in LTC should be to:

- Coordinate and access information and services,
- > Provide financial assistance, and
- Regulate/monitor quality of services.

any people do not know how to plan for their LTC needs and are confused by the many messages they hear and read. Frequently, it is not until a person needs LTC services that the individual begins to understand how these services are financed and what role the individual may need to play. As such, many individuals end up relying on Medicaid (ALTCS) after exhausting most of their life savings.

cus group comments, listed below, give the LTC system insight on how the government can help Baby Boomers plan and access long term care services and information.

- Decisions are currently being made in a crisis mode rather than in a proactive, planning mode.
- ➤ The system needs to help both full-pay individuals and those needing financial assistance to navigate the complexities of the bureaucracy.
- The state needs to develop a comprehensive approach to deal with the growing demand for LTC services.

- The government should offer case management before persons enter government programs.
- Financial eligibility needs to be changed, particularly how the government looks at assets. Consumers should not be faced with poverty or destitution before the system responds.
- ➤ Baby Boomers want more involvement in how their needs are met.
- ➤ Cultural aspects need to be considered because these aspects will affect the way individuals provide care to their family members.

Who Should be the Messenger?

ocus group participants indicated that the government, along with employers, the health care industry, social service organizations and non-profit groups, should be the messenger(s) for LTC. Currently the government is responsible for regulating and monitoring LTC providers and, as such, is in an excellent position to deliver information to consumers. Participants also suggested a LTC Coalition to be a LTC messenger. This coalition might include employers, the health care industry, social service organizations and other non-profit groups to allow for a more widely disseminated LTC message, which needs the support of many businesses and organizations.



What Should the LTC Message Be?

Baby Boomers, the LTC message should focus on the realities aging Baby Boomers face now and in the future. The message should *provide information* rather than attempt to sell a product or service. The government can be of greatest help with LTC information that enables Boomers to take proactive steps and make informed decisions about possible LTC needs.

How Should the Message be Presented?

ears ago, Marshall McLuan spoke of the "Medium in the Message."
How information is presented affects both how it is valued and how it is used to make decisions. Both the presentation format and content are crucial to help consumers make informed choices.

hat kind of message do consumers relate to?

The Baby Boomers in the focus groups said the LTC message should be:

- Simple and easy to understand (in a lay person's terms)
- Positive
- Clear and understandable
- Offered in several languages

"I hope there are happy faces. Something that makes us feels good about thinking about this LTC. I mean, nobody wants to think about somebody sitting in a chair with a diaper over them or whatever."

Baby Boomer Focus Group

- Offered in several languages
- ➤ Offered in advance of when they will need the service (either for themselves or their families)
- > Sensitive to cultural needs
- Presented in a colorful and graphic format they can relate to (not medical or depressing)
- ➤ Detailed in some areas and brief in others, with instructions on where to find additional information (such as Internet sites and location maps).

What do Arizona Baby Boomers Say about LTC?

ocus group participants were asked about the shortcomings of the current LTC system. They were asked to describe their concerns and identify what supports they need now as caregivers and what they will need in the future as consumers. The focus groups were clear on four major areas the system needs to work on: 1) information; 2) caregiving; 3) quality; and 4) services.

An ideal LTC system would provide:

Information

- ➤ Make known whom to contact to access services
- > Distribute information on choices
- Provide a centralized place to receive help in understanding choices and coordinating services
- ➤ Educate consumers on issues that impact choices and decisions
- Develop prevention messages

Caregiving

- Support the role of family and community in providing care
- ➤ Promote caregiving by family and friends rather than strangers
- > Pay family caregivers
- > Train and support caregivers

Quality

- ➤ Share with consumers information/data on care ratios of nurses/aides
- > Treat consumers with respect and dignity
- Make known whom to contact to make a complaint

- Educate consumers and about which providers are providing quality services
- ➤ Increase oversight for quality concerns
- Provide more personal service (instead of automated phone banks, etc.)

Services

- Provide prevention programs
- Provide choice of care instead of directing the kind of care that is convenient to the system
- Consistently provide services promised
- ➤ Offer more respite services
- Improve agency coordination
- Reduce waiting lists for services
- ➤ Reduce isolation
- Provide qualified and competent workers
- Maintain identity with language and culture after consumer enters the LTC system
- Explain/provide financial assistance

Does the System Need to Change to be More Aligned with Consumer Preferences?

es. Arizona is currently developing policies and principles that will guide changes in Arizona's LTC system. One of the state's major goals is to continue fostering the development of a statewide, comprehensive LTC system that maximizes independence and quality of life while recognizing the need for interdependence and support.

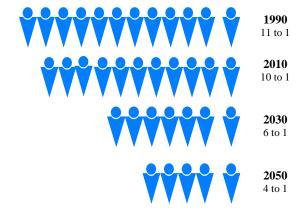
More people are living longer, a great deal longer than society has ever had to provide for in the past. Our nation needs a program that rallies existing resources and recruits new talents to meet the demographic realities facing us.

<u>Chronic Care in America</u>, Robert Wood Johnson Foundation, 1996 pproximately one in four Americans provides some kind of care to an older person with disabilities (see Figure 3). Almost 75% of the

elderly with disabilities receive home care through relatives, friends and neighbors. *Informal caregiving is still the backbone of LTC*. The role of family and the community in providing informal care will continue to be a critical component of addressing LTC needs of the elderly and disabled because of the shortage of health care professionals. The Baby Boomers will begin retiring in 2011, a trickle that over the next 20 years will become a torrent of individuals who may need care. This will further complicate the LTC labor shortage issue. The state will need to continue addressing this national and state need.

Figure 3

The Shrinking Pool of Potential Caregivers



ocus group participants categorized what was most important to them as follows:

Provide a centralized place to find LTC information;

"If you don't know the language, if you don't know who to go to from the get go, there is very little help that any one agency will give you in order to tag you into another agency. So it is not a central operation at all."

Baby Boomer Focus Group

➤ Develop a LTC message that can educate about planning and accessing services with businesses, the health industry, social service and non-profit organizations;

"Today is the tomorrow you were worried about yesterday. Today is the tomorrow you didn't worry about yesterday."

Baby Boomer Focus Group

Provide LTC information to increase the likelihood that consumers needing services will receive culturally sensitive information before they are in a crisis;

"...I would hope that this organization ...focus(es) on our ideas ...culturally and language sensitive too to embrace all peoples, as well as the blind and deaf, besides Hispanics, Asian, you name it."

Baby Boomer Focus Group

For individuals seeking to remain at home, provide more choices for in-home services including a better transportation system;

"I am not going to have to go somewhere where I am completely dependent... I can still maintain some self reliance or some independence and be of help to others and I really think this is the generation that is going to know about doing that."

Baby Boomer Focus Group

- Address quality of life within the LTC system;
- Ensure qualified caregivers that are:
 - ✓ Competent,
 - ✓ Enjoying what they do,
 - ✓ Flexible.
 - ✓ Hard working,
 - ✓ Providers of good customer service,
 - ✓ Paid well,
 - ✓ Good with people skills,

- ✓ Sensitive to individual needs,
- ✓ Reliable,
- ✓ Trustworthy, and
- ✓ Helpful to caregivers who are family and friends;

"Being Latina... I don't know if being true American or whatever that you'll agree with me or what, but most people of color don't really use a lot of nursing homes. We bring them home with us and now days we can't. I work and my husband works..."

Baby Boomer Focus Group

- > Fund additional tax incentives for LTC; and
- Create policies that do not cause consumers and families to become destitute and impoverished before they are eligible for services.

"We are all Baby Boomers going to need the care." "You shouldn't have to be in poverty or destitute before you can get any type of help. I mean it is ludicrous. You have to be out on the streets before you can get any type of aide."

Baby Boomer Focus Group



What are the Policy Issues?

CONCLUSION

he results of the focus groups were compiled into three policy issues to guide state leaders as they reform the long term care system in general and improve ALTCS in particular.

What Should be Done to Help Baby Boomers Plan for Long Term Care?

lot. Participants of both focus groups said they had put little thought into long term care for their parents, let alone themselves. They did not understand who would pay for the service when they needed it. Those with some long term care experience said that all too often they had waited until a family member was in a crisis before seeking help.

Policy Issue:

- ➤ Develop an awareness campaign to educate Baby Boomers about the need to plan, much as they already do financially for their retirement.
- Develop a better understanding of long term care financing, the makeup of the population currently receiving services and the impact on our communities.
- ➤ Hold wide-ranging discussions about the role of government in providing long term care services.



Who Needs Better Long Term Care Education and Information?

eniors, Baby Boomers, Generation Xers
- everyone. Research participants either
had no real sense about where to go for
information, or their understanding of long term
care was shallow. The few who had looked for
information said they were frustrated because
they couldn't find it, or what they did find was
not easy to understand.

Policy Issue:

- Educate, educate. Specifically, pilot a long term care education outreach program through human resource departments in a variety of businesses.
- Form partnerships to ease the flow of long term care information by creating a web site among health-related state agencies to centralize information; centralizing information at a physical location with staffing to help the public; and establishing a collaborative effort among state agencies and private organizations to distribute written material.
- ➤ Provide information that is culturally sensitive.

Who Actually can we Call the "ALTCS" Customer?

After surveying 1,031 ALTCS consumers, one result was surprising: 752 of them, or 73 percent, were proxy respondents, while only 279, or 27 percent, were actual "customers" enrolled in the program. What does this show? That proxies, or caregivers, are a valuable source of information because they are so involved with the actual user.

This finding has implications for the non-ALTCS population as well.

Policy Issue:

> State policymakers, when considering the future of ALTCS, must re-think their "customer" definition of by (1) recognizing that proxies are key customers of ALTCS; (2) performing a customer analysis of proxies; and (3) determining whether future surveys should be modified for proxies' input. Health care leaders can follow a similar approach for the non-ALTCS community.

SUMMARY

his research project has helped identify what Baby Boomers know and don't know about long term care in Arizona. In short, they need much more education and information.

ll participants in this research clearly wanted a comprehensive approach to deal with an increasing demand on long term care services in Arizona. It has been the intent of this project's working group to help this come about by defining the issues and proposing viable options for policy makers.

ARIZONA LONG TERM CARE SYSTEM (ALTCS) IN MARICOPA COUNTY

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I. INTRODUCTION/PURPOSE

The United States is one of many countries experiencing a striking demographic shift in which the fastest growing segment of the population is adults aged 65 and older. In particular, the aging cohort belongs to the Baby Boomer generation (those born between 1946 and 1964), who will begin to turn 65 in the year 2011. Along with their transition to old age come serious challenges and important consequences of an aging population. Advances in technology and medicine have allowed the longevity of life.

Currently, there are approximately 265 million people living in the United States. ¹ In 1966, there were approximately 4.5 million people living in Arizona. ² This is anticipated to increase to 9.8 million people in Arizona by 2040. ³ Currently in the United States, there is 12.8 percent of the population age 65 and older, with Arizona above the national average of persons aged 65 and older equaling 13 percent. Between 1996 and 2025, the U.S. Bureau of the Census estimates there will be an 83 percent increase among the 65 and over population. ⁴ By 2030, nearly 20 percent of the population will be age 65 and older. ⁵ The most rapid increase is expected between the years 2010 and 2030 when the Baby Boomer generation reaches age 65.

The Arizona Auditor General's report states that by 2030, almost 20 percent of the Arizona population will be 65 and older. The Arizona Long Term Care System (ALTCS) is continuing to increase at approximately seven percent a year. At the time this project started, Arizona's Health Care Cost Containment System (AHCCCS) served approximately 29,000 long term care individuals. The long term care population represents five percent of the people that AHCCCS serves, but consumes approximately 40 percent of the budget. The significant cost for this fragile population creates a high level of public and legislative viability.

The disabled population is increasing in Arizona. The consumers are demanding more community choices. The American Disabled for Attendant Programs Today (ADAPT) issued a booklet that has principles for what consumers are demanding. Some of these principles include (a) helping someone out of bed in the morning; (b) serving people in their homes rather than in a nursing home; and (c) giving people what they want rather than what professionals perceive to be their "need" because it is both less expensive and more satisfying to all concerned.^{8,9}

Long Term Care (LTC) is typically associated with individuals who are aging. However, people of all ages need LTC services. Recent estimates put the total number of Americans who are functionally impaired at about 11.5 million.¹ The population needing long term care in 1994 were .4 million children aged 0 to 18 years of age; 5.3 million adults aged 18 to 64 years of age; and 5.8 million seniors aged 65 years of age and older.²

The result of these trends is that first: the senior population will be greater in the future. Secondly, the chances of living with at least one chronic condition that impairs a person's functional ability rises significantly with age, with estimates as high as a 200 percent increase in the prevalence of chronic conditions. The result will require more long term care assistance for the "Baby Boomer" generation.

"The consumer's voice has pervaded virtually every aspect of healthcare and has advanced from a whisper to a holler." David Nash, MD, MBA, Thomas Jefferson University

In the process of studying the research questions associated with this project, credible information surfaced. The literature review produced an interesting study conducted in Minnesota entitled "Aging Initiative: Project 2030". The work done in Minnesota indicated that information is one of the key areas of interest for the "Baby Boomer" generation. The "Boomers" not only want good information sources but they want simple and credible information. The target group of "Baby Boomers" suggested that "the most credible information from government would come from a state agency and would carry multiple sponsors, including government, a business group or a major employer, and a senior citizen advocacy organization. 11

The Minnesota project found that as Baby Boomers grow older and are more concerned about their own long term care needs, they are also tending to the needs of their aging parents. They will be demanding and wanting easy access to more information about the services they are receiving. They will want more choices and policies tailored to their needs. This means government and the long term care industry must collaborate and give consumers valid and meaningful information. The current population of "Baby Boomers" is frequently confused or uninformed about the long term care services available to them or their loved ones. The result is that too often they forego services that could make a major difference in their lives or they make uninformed decisions.

AHCCCS set out to understand what forms of long term care assistance will be required by the Baby Boomer generation. To accomplish this goal, they asked Health Services Advisory Group (HSAG) to assist them in researching the kinds of services and places of residence that the Baby Boomer generation is likely to want, and to examine information, and what shifts in policy might be necessary to meet the needs of the new generation entering the long term care network.

To further explore the issues specific to Arizona's population, "Baby Boomers" were recruited to participate in two focus groups. The first intent of the focus group was to solicit information from participants on what services might be necessary for future long term care users. The second intent of the focus group was to determine the kind of information needed and to determine the best messenger of that information. The focus groups were conducted to assist Arizona in establishing the means by which long term care services will be financed and delivered in the future.

I - 2

II. METHODOLOGY

To explore issues surrounding how the "Baby Boomer" generation is thinking about long term care services and the need for long term care information, two focus groups were conducted with representatives from the Baby Boomer generation. The focus groups were used to identify issues for policy changes within the AHCCCS system, to discover what kind of LTC information consumers need, and to identify ways in which the "Baby Boomer" generation can plan for the changes that will ultimately occur in their lives.

A literature review was carried out by researchers to locate information on how States, as providers of long term care services, as well as consumers and prospective consumers, are addressing service and program needs for future consumers. Several studies have indicated that information is one of the key areas of interest for the "Baby Boomer" generation. Recent research findings reveal that the way in which information is presented often affects how it is valued and used in decisions. Both the presentation format and content are crucial to helping consumers make informed choices. Information was more likely to be used in a decision if it was presented in a way that made it easier to identify that one option is better or worse than another.¹²

"More people are living longer, a great deal longer, than any society has ever had to provide for in the past. Our nation needs a program that rallies existing resources and recruits new talent to meet the demographic realities facing us." Theodore Roszak and Beth Witrogen Mcloud

The final technique used by the project's research team was soliciting advice from the project's National Advisory Panel. The focus group handbook was forwarded to members of the National Advisory Panel for their review and recommendations. One-on-one conference calls were held with six National Advisory Panel members. This process provided insight from nationally recognized experts in the field of long term care and allowed the research team to obtain a broader perspective on the focus group questions.

A. RECRUITMENT PLAN

In October and November of 2000, HSAG recruited focus group participants from the community. The first focus group consisted of individuals who <u>had experience</u> with providing or seeking care for an older relative with a long term care system in either a private pay or government program. The second focus group consisted of individuals who <u>did not have experience</u> with providing or seeking care for a person that is older or disabled with the long term care system. Focus group participants were recruited through advertisements in local Phoenix area newspapers, community groups, and religious organizations. The inclusion criteria were based upon age, gender, ethnic breakdown, and the ability to speak English. The composition of the focus groups was proportional to the age, gender, and race/ethnicity of Arizona's Long Term Care System with the rationale for the criteria being primarily extrapolated from Arizona's Community Based Services and Settings Report, October, 2000. (Please review Appendix A for a complete demographic of the focus group criteria).

The Internet is helping to improve the quality of life for adults with disabilities, according to a recent online survey by the Harris Poll.

• 52 percent of disabled adults report the Internet has better informed them about the world versus 39 percent of adults without disabilities.

Health Care Purchaser, July 2000

B. CONDUCTING FOCUS GROUPS

Number of Focus Groups

It was recommended that a total of two focus groups be held. The first focus group consisted of 13 community "Baby Boomers" who have had experience/exposure with the LTC system. The second focus group consisted of 11 community "Baby Boomers" who had not had experience/exposure with the LTC system. The facilitator used flip charts to define the concept of long term care, and to describe the various services and settings available to individuals. This process was especially important for "Baby-Boomers" who had no experience or exposure with the LTC system.

Prior to the beginning of the focus group sessions, additional demographic questions were asked of focus group participants. This was done in order to provide a further description of participants that would be helpful during the analytical phase of the focus group.

Facilitator

A professional focus group facilitator was selected to conduct the focus groups. Representatives of the research team met in-person and via teleconference calls with the facilitator to discuss the expectations of the focus groups based upon the Focus Group Handbook. Research team representatives were also present at the focus group sessions.

Logistics

Both focus groups were held at the Health Services Advisory Group (HSAG) Conference Center. The first focus group was held on Tuesday, October 25, 2000 and the second group on Wednesday, November 1, 2000. Each focus group was audiotaped, with a subsequent transcript provided.

C. REPORTS

At the completion of the focus group sessions, the project research team prepared a detailed focus group report. The focus group report followed standard focus group methodology.

III. KEY FINDINGS

The Key Findings section outlines the goals and objectives of the focus groups (see Appendix A for a review of the complete Focus Group Handbook used in this study). Immediately following the goals and objectives is a synopsis of information that was provided to focus group participants in an effort to clarify the objectives and the questions posed to participants. Next, the actual questions asked of focus group participants are provided. A boxed side-by-side presentation of the responses from both "Baby Boomer" focus groups is displayed. Finally, policy implications are reported for each of the major areas discussed in the focus groups.

A. GOAL ONE - INFORMATION

TO PROVIDE A LONG TERM CARE MESSAGE THAT WILL HELP CONSUMERS MAKE INFORMED LONG TERM CARE CHOICES TO MEET THEIR OWN NEEDS

Objective One: Describe the importance of accessing information on long term care services.

There is a growing body of research indicating that Baby Boomers are consumed by day-to-day activities and expenses and, as such, have given little thought to planning for long term care or nursing home needs. In a 1997 focus group held in Minnesota, Baby Boomers were characterized by the "theory of invincibility," meaning they have convinced themselves that they will probably never have to go to a nursing home or need long term care. As evidenced by the issues faced by our parents and today's seniors, planning for long term care services has become a necessity for Baby Boomers.

"I have been planning for my retirement and death. No one told me to plan for long term care." Chronic Care in America, Robert Wood Johnson Foundation, 1996.

The following set of questions were posed to focus group participants regarding the importance of accessing information about LTC services:

- **A.** If you found it hard to locate the LTC information, what were the key problems you found in the LTC system?
- **B.** Where did you go to locate LTC information?
- **C.** Who would you turn to for LTC information?
- **D.** What would make it easier to get LTC information?

(Responses in the boxed side-by-side presentations are labeled to correspond with the letter assigned to each question).

Participants who had been exposed to LTC	Participants who had not been exposed to LTC
A - Locating facility for consumer recently	A - Difficult to locate information – they do
discharged from hospital	not know where to go
A - Necessary to access multiple organizations	A - Do not understand the LTC system
A - Unable to get information relating to	including the funding aspect
placement of a consumer	

Participants who had been exposed to LTC

- **A** Inability to get referrals
- **A** Complications in understanding supplemental insurance
- **A** System is not user-friendly
- **A** Scattered approach to disseminating information
- A Consumers "give-up" or simply "wait-out" the system until they receive the information on LTC services that they need
- **B** Accessed social workers at hospitals but they are too busy to help consumers and their families access the information relevant to placement
- \mathbf{C} Hospitals
- C All families should have an "advocate"
- C Social workers
- **D** Need information so they can perform a background check on potential caregivers
- **D** Create a central processing system
- **D** System should be accessible through telephone, mail, Internet, and brochure
- **D** System to be responsive to "urgent" requests
- **D** Create a system that can direct individuals to the right agency, at the most appropriate time, and for the eligible service

Participants who had not been exposed to LTC

- **B** Among the first calls to be made in search for long term care services were:
 - Insurance company
 - Hospital
 - Health clinic
 - Social worker
 - Nursing facility
- C Use government and non-profit organizations to provide a more independent approach to the quality of a product/service
- **D** Current consumers need to access former consumers so they know what questions need to be asked and where to look for information
- **D** Non-bias opinion regarding quality of health products/services should be available

Objective Two: Understand what mode of communication is most effective in educating the public about LTC.

Messages on long term care should focus on the realities that Baby Boomers themselves may face and should concentrate on providing information, not on selling a product. It is important that Baby Boomers be provided with knowledge regarding long term care issues so they can make informed decisions and take the necessary actions for planning appropriately for their long term care needs. Listed below are the two questions pertaining to the mode of communication that were asked of focused group participants.

- **A.** What communication techniques (e.g., brochure, Internet, magazine, newspaper, telephone, letter, television, and radio) do you prefer when seeking out information about programs or services?
- **B.** Who is the best messenger for delivering information to the public about LTC? (e.g., government, public sector, private sector, non-profit organizations)?

Participants who had been exposed to LTC	Participants who had not been exposed to LTC
A - Workshop settings (e.g., retirement	A - Employer (expand current workshops on
workshops)	retirement planning to include LTC
A - Religious group functions	services)
A - Health related workshops or seminars	A - Bring in experts to the workshops
A - Information available in their early forties	A - Disseminate through print media such as
to plan appropriately	newspapers, journals, and brochures
A - Disseminate through television, brochure,	
and telephone	B - Government since they regulate and/or
A - Form coalition with healthcare industry,	monitor health care providers
employers, social service organizations,	B - Either the government or non-profit group
and other organizations	- A "real-person" needs to be available to
	answers consumer questions
B - Non-profits	
B - Physician's office	
B – Motor vehicle license renewal	
B - Social Security offices	
B - Peer groups	
B - Medical community	

I. Objective Three: To determine what content should be included in the mode of communication about LTC services and where the information should be located.

There is an array of communication techniques available to get the "message" out to Baby Boomers about the need to think and plan for LTC. Some research indicates that Baby Boomers are receivers of this kind of information, although they will not necessarily actively seek it. Research also indicates that consumers are receptive to information built upon a concise format with clear and understandable content. Listed below are the questions pertaining to what content should be included in the mode of communication asked of focus group participants.

- **A.** What information would you be looking for? What settings, eligibility criteria?
- **B.** How do you think the LTC information should be formatted? (e.g., large print, color, pictures)

Participants who had been exposed to LTC	Participants who had not been exposed to LTC
A - Use the telephone book as an option to provide a categorization of services and programs available in LTC	A - Provide consumer with a good representation of the available services, programs, and settings
A - Options should be provided to identify where a consumer can go for further information	 A - Eligibility criteria for various programs A - Define the levels of care A - Indicate whom a consumer can call for more information:
B - Lots of color to attract reader	 List basic questions that should be asked by consumers of facilities or programs Map out the locations of the various facilities Waiting list time Short-term vs. long term care programs A - Include assessment tool so a consumer can measure the facility and/or program B - Available in languages other than English B - Detail oriented
	 B - Easily understood language, layman's terms. B - Color and graphics B - Pictures that depict the main theme of the brochure

B. GOAL TWO -SERVICES

DEVELOP A STRATEGY ON HOW TO PLAN FOR THE FUTURE OF ARIZONA'S LONG TERM CARE SYSTEM BASED ON CONSUMER INPUT.

Objective One: Determine a vision that clearly states the principles and polices that will assist the individual with access to an appropriate long term care system.

The focus group included a discussion on the program and policies regarding long term care. It was agreed that such programs and policies, as have been identified throughout the focus group session, are complicated and difficult to comprehend. Additionally, there are those who say the system needs to change to be more aligned with consumer preferences. Some states have adopted sets of guiding principles that are used to assist in the planning, recommendations, implementation, monitoring, and evaluation phases of long term care changes occurring throughout the country.

Arizona is developing policies and principles that will guide changes in Arizona's Long Term Care System. One of the major goals is to foster the development of a statewide and comprehensive long term care system, and maximize independence and quality of life while at the same time recognizing the need for interdependence and support. Listed below are two questions asked of focus group participants relating to Objective One.

- **A.** What do you think are the shortcomings of the current long term care system in Arizona?
- **B.** What is most important for Arizona to plan for to meet consumer needs and preferences for the future LTC?

Participants who had been exposed to LTC

- **A** Consumers have not always received a service that the LTC system committed to provide
- A Programs are short-staffed.
- A Consumers are not aware that nursing facilities and home and community-based services are monitored and what reporting systems are utilized by the State to ensure quality
- A A certain level of competence within nursing facilities and home and community-based services is not mandated or encouraged
- **B** Disseminate information and examine the issue of accountability on the policies and procedures used for the proper use of medications

Participants who had *not been* exposed to LTC

- **A** Concerned about the level of abuse in nursing homes (as reported by television media)
- **A** Care ratio for number of nurses to patients is not identified and shared with the public
- **B** Increase inspections to ensure compliance with government rules and regulations
- **B** Develop a prevention program so more consumers can spend less time in nursing home facilities and more time in their own homes
- **B** Create a system of interdependency. For example, allow important friends and families (the caregiver) of consumers to provide the necessary home services and receive financial assistance to ensure that services are based on quality

- **B** Minimizing medication errors, length of waiting lists for nursing facilities and home and community-based services
- **B** Funding issue (i.e., thought Medicare would pay). Educate consumers on how the issue of funding will impact their choices and decisions
- **B** Lack of agency coordination

- **B** Provide an effective respite system for caregivers
- **B** Provide respect and dignity to family and friends as they are more likely to be delivering services

Objective Two: To understand what is the most important issue to the consumer in building family and community support.

Approximately one in four Americans provide some kind of care to an older person with disabilities. Almost 75 percent of the elderly with disabilities receive home care through relatives, friends, and neighbors. Informal caregiving is still the backbone of long term care, per National Governor's Association of Best Practices. As parents age, they are at risk for long term chronic illnesses and expenses. The role of family and the community in providing informal care will continue to be a critical component of addressing the LTC needs of the elderly and disabled. Listed below are two questions asked of focus group participants pertaining to the help needed by family/caregivers, and concerns regarding the need for LTC.

- **A.** What help (e.g. caregiving, sensitivity training, support) do you think families/caregivers need so they can effectively provide care for a loved one?
- **B.** What concerns do you have about your own possible need for long term care?

Participants who had been exposed to LTC	Participants who had not been exposed to LTC
A – Advocacy	A - Emphasize the role of family and
A - Training and support groups for care	community in providing informal care
providers	A - Support group for caregivers
A - Educating care providers regarding the	A - Respite care
changes in a long term care system	A - Provide counselors to in-home providers,
A – Education on how to maintain identity	such as a friend or a relative
with language and culture for consumers	A - Provide monetary structure to family,
A - Respite care	friends and neighbors who provide care
A - Form coalitions with the health care	
industry, employers, social service	B - Caregivers need a "call center" they can
organizations, and other organizations to	call to get help in dealing with and/or
allow for a more widely disseminated	addressing the needs of a consumer
message on LTC	B - Want ability to choose their care instead of
A - Sensitivity placed on cultural, language,	being directed to the type of care that is
gender, race/ethnicity, age, and disability	convenient for the system
status	B - Qualified and trained individuals taking
A - Provide monetary structure to family,	care of the consumers

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- **B** Knowing whom to contact within the "system" to access a service or make a complaint
- **B** Recognize consumers for their uniqueness
- **B** Reduce the level of isolation felt among consumers
- **B** Want financial components of care covered
- **B** Create a system that enables consumers to receive a high level of care, when a consumer can no longer speak on behalf of himself or herself

Objective Three: To understand what consumers view as the roles of the private sector, public sector, and consumer and families.

There are many opinions, especially in an election year, regarding the role of the government, the private sector, the public sector, and individuals when it comes to paying for health care services. This is especially true for LTC services. Many people are unaware of how they should be planning for their future LTC needs and are also confused by many messages they hear and read about pertaining to this subject. Unfortunately, it is not until a person needs LTC services that he/she begins to understand how LTC services are financed and the role the individual may need to play. As such, many individuals end up relying on Medicaid (AHCCCS in Arizona) after they have exhausted most of their life savings and assets to become eligible for Medicaid.

Consumer concerns have been raised at the national and local levels regarding quality of care in long term care. The government is the primary regulator of long term care providers. This oversight by government includes monitoring of quality, licensing of providers, inspections, investigations, and mandatory reporting of abuse or neglect, and client satisfaction surveys. Listed below is the question asked of focus group participants pertaining to the role of the private and public sector.

A. What would you tell legislators about the need for long term care services (local, state, federal) in long term care?

Participants who had been exposed to LTC

- **A** Decisions are made in crisis mode rather than proactively planning for future long term care services
- A Develop a comprehensive approach in how the State will deal with the impact of "Baby Boomers"
- **A** Develop approach to include the eligibility criteria for accessing services whether consumers are on government or private-pay plans/programs

Participants who had not been exposed to LTC

- **A -** Work with legislators on how rules and regulations are designed and written
- **A** Consumers should not be faced with poverty or be destitute before the system responds with some form of help
- A Fund an additional tax for long term care as a possible solution to funding long term care for Baby Boomers

Objective Four – Understand what consumer's preferences, needs and values are regarding the long term care choices, alternatives, services, and settings.

Focus group participants were provided with a listing of the definitions of the current services and placement settings available to long term care consumers (Appendix C). Focus group participants discussed what they felt were the most important qualities in selecting a caregiver to care for themselves or a loved one. The qualities include trust, background check, education, flexibility, experience, sensitive, someone that can think independently, enjoy what they do, people skills, professionalism, and customer service aimed specifically at the elderly.

Consumers prefer LTC services be delivered in home and community settings. Expanding the number of alternatives, services and settings may provide the opportunity to better match a consumer's needs and preferences with service options that allow the consumer to live in the most integrated setting possible. Listed below are the questions asked of the focus group participants pertaining to what consumers prefer, need and value regarding long term care.

- **A.** What LTC services are important to you?
- B. What LTC services should be added so you can live in the most integrated setting possible?C. What is the most important factor in choosing someone or a provider (e.g., personal care aide, attendant, doctor) to care for you or a loved one?

Participants who had been exposed to LTC	Participants who had not been exposed to LTC
A - Home services	A - Attendant care
A - Transportation	A - Home health services
A - Attendant care	A - Home delivered meals
A - Housekeeper	A - Transportation
A - Nurse	
 C - Trust C - Qualifications C - Background check, education C - Flexibility C - Experience C - Sensitivity C - A person that can think independently, enjoy what they do C - People skills, professionalism C - Customer service aimed specifically at 	 B - Create policies that do not call upon consumers being in poverty in order to receive long term care services B - Quality at all levels of care within the system C - A strong sense of ethics C - Not abusive C - Paid well C - Have the ability to take the initiative in handling problems C - Reliable and reputable
the senior consumer	C - Hard workerC - Responsible personC - A professional

IV. FOCUS GROUP PARTICIPANT RECOMMENDATIONS

The following recommendations were highlighted from two "Baby Boomer" focus groups recently held in Arizona. Among the recommendations and/or findings are: (1) planning for long term care services centers around a crisis and as such many individuals rely solely upon Medicaid (AHCCCS in Arizona) to provide them with all their services; (2) accessing information is difficult and cumbersome; (3) there is an array of communication techniques available to long term care systems so information can be provided in an effective and meaningful manner; (4) there are shortcomings in the current system and these should be addressed; and (5) the role of family and community in providing informal care will continue to be a critical component of addressing LTC needs of the elderly and disabled.

A unique component of this project is our ability to compare participants with and without exposure to the LTC system. What follows is a brief analysis of these two groups on key issues.

Participants who *had been exposed* to the LTC system listed many more problems in locating LTC information than did those participants who *had not been exposed* to LTC. However, those participants without exposure tried to locate LTC information from "usual" or "expected" sources but were unable to access the information. This leads us to conclude that irrespective of a person's experience with ALTCS, accessing needed LTC information is problematic. A centralized system needs to be created as quickly as possible to address the issue of accessing long term care information.

When looking for information, focus group participants who *had not been exposed* to the LTC system provided much more detail regarding their informational needs. It is difficult to assess why this difference is so pronounced, except to say that "Baby Boomers" will want a good deal of information so they can make informed choices.

Both focus groups highlighted specific current shortcomings and future needs and preferences. For those participants who *had been exposed* to LTC, they expressed concern over the lack of enough staff to handle the needs of consumers (in facilities and at home) and were also concerned regarding quality oversight. For those participants who *had not been exposed* to LTC, the issues were much different as they called for the development of prevention programs. Prevention programs could lead to a smaller ratio of consumers in nursing facilities, thereby reducing the cost of services and increasing one's quality of life.

Participants with and without exposure to the LTC system were equally concerned about the role of family, friends, and neighbors. Recognition and support for the informal care structure, which has been inherent in the LTC system, is necessary. A recommendation receiving support from both groups was a monetary structure system for all caregivers. Additionally, emphasis was placed on the need to provide a variety of support services (i.e., respite care, training, education on the changes in the LTC system) to caregivers.

The role of family and community in providing informal care cannot be underestimated in the LTC setting. Focus group participants consistently identified the need to provide more support for the informal setting, which is the backbone of a LTC system. Caregivers need to be acknowledged for the work they do and should be provided with both an adequate salary and

education on how to work within the LTC system. It was also recognized by focus group participants that language and cultural identity need to be maintained.

All participants clearly want legislators to develop a comprehensive approach in how Arizona will deal with the influx of Baby Boomers on the LTC system. The two groups of participants did not show any differences in what types of services they consider important and necessary. However, focus group participants who *had not been exposed* to the LTC system were extremely worried about consumers being destitute before they can receive services. Education in this area appears to be an immediate task before the LTC system.

V. CONCLUSION

The results of the focus groups were compiled into three policy issues to guide state leaders as they reform the long term care system in general and improve ALTCS in particular. In late 2001, the research team will re-interview the initial respondents by telephone with the same survey tool. Data will be compared to the current consumer survey, which will function as the base line tool. At that time, a comparison report of the new findings will be shared with the community.

Three Policy Issues

A. WHAT SHOULD BE DONE TO HELP BABY BOOMERS PLAN FOR LTC?

Alot. Participants of both focus groups said they had put little thought into long term care for their parents, let alone themselves. They did not understand who would pay for the service when they needed it. Those with some long term care experience said that all too often they had waited until a family member was in a crisis before seeking help.

Policy Issue:

- Develop an awareness campaign to educate Baby Boomers about the need to plan, much as they already do financially for their retirement.
- Develop a better understanding of long term care financing, the makeup of the population currently receiving services and the impact on our communities.
- Hold wide-ranging discussions about the role of government in providing long term care services.

B. WHO NEEDS BETTER LTC EDUCATATION AND INFORMATION?

Seniors, Baby Boomers, Generation Xers - everyone. Research participants either had no real sense about where to go for information, or their understanding of long term care was shallow. The few who had looked for information said they were frustrated because they couldn't find it, or what they did find was not easy to understand.

Policy Issue:

- Educate, educate. Specifically, pilot a long term care education outreach program through human resource departments in a variety of businesses.
- Form partnerships to ease the flow of long term care information by creating a web site among health-related state agencies to centralize information; centralizing information at a physical location with staffing to help the public; and establishing a collaborative effort among state agencies and private organizations to distribute written material.
- Provide information that is culturally sensitive.

C. WHO ACTUALLY CAN WE CALL THE "ALTCS" CUSTOMER?

After surveying 1,031 ALTCS consumers, one result was surprising: 752 of them, or 73 percent, were proxy respondents, while only 279, or 27 percent, were actual "customers" enrolled in the program. What does this show? That proxies, or caregivers, are a valuable source of information because they are so involved with the actual user. This finding has implications for the non-ALTCS population as well.

Policy Issue:

• State policymakers, when considering the future of ALTCS, must re-think their definition of "customer" by (1) recognizing that proxies are key customers of ALTCS; (2) performing a customer analysis of proxies; and (3) determining whether future surveys should be modified for proxies' input. Health care leaders can follow a similar approach for the non-ALTCS community.

IN SUMMARY

This project has helped iddentify what Babay Boomers know and don't know about long term care in Arizona. In short, they need much more education and information.

All participants in this research clearly want a comprehensive approach to deal with an increasing demand on long term care services In Arizona. It has been the intent of this project's working group to help this come about by defining the issues and proposing viable options for policy makers.

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APPENDIX A

COMPARISON OF FOCUS GROUPS ON DEMOGRAPHICS

Focus Group # 1 Participants	Focus Group # 2 Participants
Ethnic Background	Ethnic Background
• Native American – 1	Native American – 1
• African American – 2	African American – 2
• White − 8	• White − 6
• Hispanic – 2	• Hispanic – 2
Gender	Gender
• Males – 4	• Males − 4
• Females – 9	• Females – 8
Mean Age – 46.7 Years Old	Mean Age – 42.4 Years Old

Focus Group # 1 Education	Focus Group # 2 Education
• Some College (23%)	• Less than High School (8%)
• College Graduate (31%)	High School Graduate (8%)
• Post Graduate (46%)	• Some College (50%)
	College Graduate (17%)
	• Post Graduate (17%)

Focus Group # 1 Marital Status	Focus Group # 2 Marital Status
• Married (31%)	• Married (31%)
• Divorced (38%)	• Divorced (42%)
• Single (31%)	• Single (25%)

Focus Group # 1 Annual Income	Focus Group # 2 Annual Income
• \$20,000 to \$29,999 (23%)	• \$20,000 to \$29,999 (17%)
• \$30,000 to \$39,999 (15%)	• \$30,000 to \$39,999 (17%)
• \$40,000 to \$49,999 (8%)	• \$40,000 to \$49,999 (17%)
• \$50,000 to \$74,999 (46%)	• \$50,000 to \$74,999 (32%)
• \$75,000 + (8%)	• \$75,000 + (17%)

APPENDIX B

AHCCCS LONG TERM CARE CONSUMER SATISFACTION PROJECT

FOCUS GROUP HANDBOOK

October 24, 2000

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BACKGROUND TO THE DEVELOPMENT OF FOCUS GROUP QUESTIONS

The focus group questions recommended in this handbook are for use by the AHCCCS Long Term Care Consumer Satisfaction Project. The questions were designed specifically for "Baby Boomer" focus groups. The first intent of the focus group is to solicit information from participants on what services may be necessary for future ALTCS users. The second intent of the focus group is to conclude what information should/should not be included in a brochure to provide general and/or specific long term care information.

A literature review was carried out to locate information on how states, as providers of long term care services, as well as clients and prospective clients, are addressing service and program needs for future clients. A specific group shortly to be affected is the "baby boomer" generation. How will/are states preparing for the influx of this generation? Will new financial mechanisms be necessary to provide services? What services will be made available to qualified individuals? What is the role of individuals in planning for their own LTC needs? These and other questions need to be examined as Arizona faces a pivotal juncture in how long term care services will be financed and delivered. One of the primary focuses of this literature review was to gather information and/or insight on how researchers use "baby boomers" in a focus group setting to solicit information. Unfortunately, the literature was weak on this particular point and as such the research team relied upon findings in the literature that dealt with structure and composition of focus groups, and its' settings, for sensitive groups and about sensitive issues.

Additionally, the literature review included an extensive review of Project 2030, an Aging Initiative by the Minnesota Department of Human Services. The project, one of a kind in the nation, was a public awareness campaign to encourage a shared understanding of the long term care needs and cost implications for the future. The research methodology utilized in Project 2030 was very comprehensive utilizing four distinct methodologies. Of interest to the project's research team was the focus group methodology used in Project 2030 specific to the kinds of information that "babyboomers" want with reference to LTC.

A second technique used by the project's research team in the development of focus group questions was holding a "brainstorming session" with AHCCCS staff members. Approximately twenty AHCCCS staff members came together with two members of HSAG's research team to discuss what issues were worthy of exploring so ALTCS could be a responsive system to "baby boomers" as they enter the system. Experienced facilitators brought participants of the brainstorming session together by having them list items they believe impact the use of long term care services and programs for "baby boomer" clients. This item identification process concluded with participants coming to agreement on three main categories they believe succinctly categorize the future issues of long term care in Arizona.

The final technique used by the project's research team was soliciting advise from the project's National Advisory Panel. The focus group handbook was forwarded to members of the National Advisory Panel for their review and recommendations. One-on-one conference calls were held with five National Advisory Panel members. This process provided insight from nationally recognized experts in the long term care field and allowed the research team to obtain a broader perspective on the focus group questions.

GOAL ONE: TO PROVIDE A LONG TERM CARE MESSAGE THAT WILL HELP CONSUMERS MAKE INFORMED LONG TERM CARE CHOICES TO MEET THEIR OWN NEEDS.

Objective 1: To describe the importance of accessing information on long term care services.

Lead-in

There is a growing body of research indicating that baby-boomers are consumed by day-to-day activities and expenses and, as such, have given little thought to planning for long term care or nursing home needs. In a 1997 focus group held in Minnesota, baby-boomers were characterized by the "theory of invincibility," meaning they have convinced themselves that they will probably never have to go to a nursing home or need long term care. As evidenced by the issues faced by our parents and today's seniors, planning for long term care services is a necessity for baby-boomers.

Questions

[Facilitator: Use the flip chart to define long term care services.]

What is Long Term Care? Long term care is any service or support that a person needs because a disability or chronic illness limits his or her ability to do the everyday things in life, such as bathing, eating, dressing, using the toilet, or moving around one's living environment. Long term care can be provided in many settings, including: a person's own home; a nursing home; a residential facility such as a group home, community based residential facility, assisted living facility, or adult family home; or a community setting such as adult day care or the workplace.

Please ask the following questions using two distinct endings. The first ending is for self as a consumer; and the second ending is for self as a caregiver. For example – Do you find it hard to locate LTC information as a consumer? Do you find it hard to locate LTC information as a caregiver?]

For Baby-Boomer Group #1 (those with exposure/experience to LTC) please phrase the questions as follows:

- If you found it hard to locate the LTC information, what were the key problems you found in the LTC system? *
- 2. If you arranged for LTC services, whom did you turn to for LTC information?
- 3. What would make it easier to get LTC information?

^{*} Key Questions

For Baby-Boomer Group#2 (those with no exposure/experience to LTC) please phrase the questions as follows:

- 1. Have you ever tried to locate LTC information?
- 2. Were you successful in locating the LTC information?
 - > Tell me about your experience.

[Facilitator: Please use the following questions as prompts if needed.]

- 3. Did you find it hard to locate LTC information?
- 4. Where did you go to locate LTC information? *
- 5. Who would you turn to for LTC information? *
- 6. What would make it easier for you to get LTC information?

Objective 2: To understand what mode of communication is most effective in educating the public about LTC.

Lead-in

Messages on long term care should focus on the realities that baby-boomers may face themselves and should concentrate on providing information, not on selling a product. It is important that baby-boomers be provided with knowledge regarding long term care issues so they can make informed decisions and take the necessary actions for planning appropriately for their long term care needs.

Questions

[Facilitator: Please use flip chart detailing the various communication techniques as listed below]

- What communication technique (e.g., brochure, Internet, magazine, newspaper, telephone, letter, television, and radio) do you prefer when seeking out information about programs or services?
- 2. Who is the best messenger for delivering information to the public about LTC? (e.g., government, public sector, private sector, non-profit)? *
- * Key Questions
- 3. What sound bite can we use to educate people about LTC services?

[Facilitator: Ask this question if needed or time permits]

Objective 3: To determine what content should be included in the mode of communication about LTC services and where should information be located.

Lead-in

There is an array of communication techniques available to get the "message" out to baby-boomers about the need to think and plan for LTC. Some research indicates that baby-boomers are receivers of this kind of information, although they will not necessarily actively seek it. Consumers are receptive to information built upon a concise format with a clear and understandable content.

Questions

- 1. What information (general, specific or both) would you be looking for? *
- 2. How do you think the LTC information should be formatted? (e.g., large print, color, pictures)
- 3. What makes you pick up a brochure (e.g., narrative, testimonials, pie charts, and fun message)?

^{*} Key Questions

GOAL TWO: TO DEVELOP A STRATEGY ON HOW TO PLAN FOR THE FUTURE OF ARIZONA'S LONG TERM CARE SYSTEM BASED ON CONSUMER INPUT.

Objective 1: To determine a vision that clearly states the principles and policies that will assist the individual with access to an appropriate long term care system.

Lead-in

The program and policy terrain of long term care is complicated. There are those who say the system needs to change the array of alternatives, services and settings to be more aligned with consumer preferences. Some states have adopted sets of guiding principles that are used to assist in the planning, recommendations, implementation, monitoring and evaluation of long term care change.

Arizona is developing policies and principles that will guide changes in Arizona's long term care system. One of the major goals is to foster the development of a statewide and comprehensive long term care system that maximizes independence and quality of life, while at the same time recognizing the need for interdependence and support.

Questions

- 1. What do you think are the shortcomings of the current long term care system in Arizona? *
- 2. To meet consumer LTC needs and preferences for the future, what is most important for Arizona to plan for? *

Objective 2: To understand what is most important to the consumer in building family and community support.

Lead-in

Approximately one in four Americans provide some kind of care to an older person with disabilities. Almost 75 percent of the elderly with disabilities receive home care through relatives, friends, and neighbors. Informal caregiving is still the backbone of long term care. As you age, you are at risk for long term chronic illnesses and expenses. The role of family and the community in providing informal care will continue to be a critical component of addressing the LTC needs of the elderly and disabled.

* **Key Questions** Questions

- What help (e.g., caregiving and sensitivity training's, support groups, socialization)
 do you think families/caregivers need so they can effectively provide care for a loved
 one? *
- 2. What concerns do you have about your possible need for LTC services and settings?

Objective 3: To understand what consumer's view as the roles of private sector, public sector, and consumer and families.

Lead-in

There are many opinions, especially in an election year, regarding the role of the government, private sector, public sector, and individuals when it comes to paying for health care services. This is especially true for LTC services. Many people are unaware of how they should be planning for their future LTC needs and are also confused by many messages they hear and read about pertaining to this subject. Unfortunately, it is not until a person needs LTC services that people begin to understand how LTC services are financed and the role the individual may need to play. As such, many individuals end up relying on Medicaid (AHCCCS in Arizona) after they exhausted most of their life savings and assets to become eligible for Medicaid.

Questions

1. What would you tell legislators about the need for LTC services?

[Facilitator: It is important that we ascertain the form of government being referenced from participants offering an answer to this question. If we probe to each level of government, we will need to be aware of the potentially long time it will take to answer this question.]

Objective 4: To understand what consumer's preferences, needs and values are regarding the long term care choices, alternatives, services and settings.

Lead-in

We have provided you with current options and definitions of settings in the handout you have. What other services would you like to see that are not listed? What long term care services should be provided so you could live where you wish to live?

* Key Questions

[Facilitator: Refer to handout to share the following service and setting definitions with participants.]

Service Definitions

Attendant Care: A service provided by a trained attendant for members who reside in their own homes and which may include homemaker services, personal care, coordination of services, general supervision and assistance, companionship, socialization and skills development.

Home Delivered Meals: A service that provides a nutritious meal containing at least one-third of the federal recommended daily allowance for the member, delivered to the member's own home.

Home Health Services: Part-time or intermittent care for members who do not require hospital care; this service is provided under the direction of a physician to prevent rehospitalization for institutionalization and may include skilled nursing, therapies, supplies, and home health aide services.

Homemaker: A service that provides assistance in the performance of routine household activities such as shopping, cooking, and running errands.

Personal Care: A service that provides assistance with personal physical needs such as washing hair, bathing, and dressing.

Respite Care: A service that provides short-term care and supervision to relieve primary caregivers.

Setting Definitions

Adult Foster Care: An approved alternative residential setting that provides room, board, supervision, and coordination of necessary services within a family type environment for up to four adult residents.

Assisted Living Home (commonly referred to as Adult Care Home): An approved alternative residential setting that provides resident rooms to ten or fewer residents.

Assisted Living: An approved alternative residential setting that provides a private apartment, unless otherwise requested by a resident, that includes a living and sleeping space, kitchen area, private bathroom, and storage area.

Behavioral Health Level II: A behavioral health service agency licensed by the Arizona Department of Health Services to provide a structured residential setting with 24-hour supervision and counseling or other therapeutic activities for individuals who do not require the intensity of treatment services or on-site medical services found in a Level I facility.

Questions

- 1. What LTC services are important to you?
- 2. Are there any LTC services that should be added so you can live where you want to live?
- 3. What is the most important factor in choosing a caregiver to care for you or a loved one? *

Closing Question

We have discussed a lot of issues surrounding LTC services tonight, is there anything else you would like to share with us?

^{*} Key Questions

Thank you for participating in this Focus Group. The Focus Groups were made possible through a grant from the Flinn Foundation.

RECRUITMENT PLAN

The recruitment plan consists of two "baby-boomer" groups. The first "baby-boomer" group is defined as individuals who have had exposure or experience with the LTC system. The second group consists of "baby boomers" that have not had exposure or experience with the LTC system.

Both community "baby boomers" will be recruited through advertisements in local Phoenix area newspapers. Each "baby boomer" focus group participant will receive \$50 for participating in the focus group. A light refreshment will also be served. The inclusion criteria are based upon age, gender, race/ethnicity, and the ability to speak English. The composition of the focus groups is proportional to the age, gender, and race/ethnicity of ALTCS. Rationale for criteria was primarily extrapolated from Arizona's Community Based Report, August 2000. Please review Table 1 for a complete description of the focus group criteria.

Additional demographic questions will be asked of focus group participants prior to the start of the focus group. This will be done in order to provide a further description of participants that will be helpful during the analytical phase of the focus group.

Table 1

Category		Baby Boomers With Experience/Exposure to the System n=12-15		Baby-Boomers Without Experience/Exposure to the System n=12-15	
<u>Age</u>	Rationale for Criteria	Birthday year 1946 - 1962.		Birthday year 1946 – 1962.	
	Focus Group Inclusion Criteria	38-54 years of age		38-54 years of age	
<u>Gender</u>	Rationale for Criteria	Arizona's Community Based Report		Arizona's Community Based Report	
	Focus Group Inclusion Criteria	Male Female Male	33% 67% 3	Male Female Male	35% 65% 3
		Female	7	Female	7
Race/ Ethnicity	Rationale for Criteria	Arizona's Community Based Report		Arizona's Community Based Report	
	Focus Group Inclusion Criteria	Asian Pacific Black Caucasian Hispanic Native Am Other	1% 5% 71% 15.05% 7% .95%	Asian Pacific Black Caucasian Hispanic Native Am Other	1% 5% 71% 15.05% 7% .95%
	i cous Group moidsion officia	Asian Pacific Black Caucasian Hispanic Native Am Other	0 1 6 2 1 0	Asian Pacific Black Caucasian Hispanic Native Am Other	0 1 6 2 1 0

CONDUCTING FOCUS GROUPS

Number of Focus Groups

It is recommended that a total of two focus groups be held. The first focus group will consist of 12-15 community "baby boomers" who have had experience/exposure with the LTC system. The second focus group will consist of 12-15 community "baby boomers" who have not had experience/exposure with the LTC system. It is important that the facilitator use appropriate flip charts to define the concept of long term care, and to describe the various services and settings available to individuals. This process will be especially important for "baby-boomers" who had no experience or exposure with the LTC system.

<u>Facilitator</u>

A professional focus group facilitator has been secured to conduct both focus groups. Representatives of the research team met in-person and via conference calls with the facilitator to discuss the expectations of the focus groups based upon the Focus Group Handbook. Research team representatives will also be present at the focus groups.

Logistics

Both focus groups will be held at Health Services Advisory Group. The first focus group will be held on Tuesday, October 25, 2000 and the second group on Wednesday, November 1, 2000. Each focus group will be audiotaped.

REPORTS

Upon completion of the focus groups, the research team will take responsibility for preparing a detailed focus group report. The focus group report will follow standard focus group methodology. Upon approval of the report by the project's Research Subcommittee, the report will be submitted to AHCCCS for their review and approval.

Final Report

In addition to the findings of the focus group that will be prepared, the final focus group report will be complemented by a: (1) synthesis of literature review findings pertaining to focus groups and long term care issues, (2) description of the focus group criteria, (3) synopsis of the Focus Group Handbook, and (4) review of the Focus Group Handbook conducted by the National Advisory Panel. The final product will be a comprehensive report encompassing all these elements.

AHCCCS Focus Group Handbook

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APPENDIX C

Service Definitions

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ABOUT THE BABY BOOMER FOCUS GROUPS

To learn more about how to strategically plan for the future of our long term care systems in Arizona, the Flinn Foundation funded the first state Medicaid long term care baby boomer focus groups.

ABOUT THE DATA

The qualitative data presented in this report was collected from the participants of two Baby Boomer focus groups. The first group had experience with providing or seeking care for an elder relative within the LTC system in either a private pay or government program. The second focus group consisted of individuals who did not have experience with LTC.

ABOUT THE EXECUTIVE SUMMARY

This series, Baby Boomers: Who Me? (Focus Groups), is funded by a grant from The Flinn Foundation.

This report is the fourth in a series of six publications. Other documents available are:

- 1. What the Experts Say? (Literature Review)
- 2. What Current Consumers Say (Survey Book)
- 3. Survey Data Book
- 4. Final Report: Now and the Next Generation
- 5. Trifold Final Report Summary: Now and the Next Generation







For more information, please contact:

Arizona Health Care Cost Containment System (AHCCCS) 801 E. Jefferson, M/D 4200 Phoenix, Arizona 85034

www.ahcccs.state.az.us







This report has been a joint effort of three organizations.

AHCCCS, HSAG, and Flinn Foundation.

The intent has been to define the issues and propose viable options for policy-makers regarding long term care in Arizona.

Additional copies can be obtained from the AHCCCS website at www.ahcccs state.az.us.

Long Term Care: Now and the Next Generation:

Final Report
Final Report Summary
Baby Boomers: Who Me?
What the Consumers Say
What the Experts Say
Survey Data Book